

Cross-cultural Similarities and Differences in Attitudes About Advance Care Planning

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OBJECTIVE: Culture may have an important impact on a patient's decision whether to perform advance care planning. But the cultural attitudes influencing such decisions are poorly defined. This hypothesis-generating study begins to characterize those attitudes in 3 American ethnic cultures.

DESIGN: Structured, open-ended interviews with blinded content analysis.

SETTING: Two general medicine wards in San Antonio, Texas.

PATIENTS: Purposive sampling of 26 Mexican-American, 18 Euro-American, and 14 African-American inpatients.

MEASUREMENTS AND MAIN RESULTS: The 3 groups shared some views, potentially reflecting elements of an American core culture. For example, majorities of all groups believed "the patient deserves a say in treatment," and "advance directives (ADs) improve the chances a patient's wishes will be followed." But the groups differed on other themes, likely reflecting specific ethnic cultures. For example, most Mexican Americans believed "the health system controls treatment," trusted the system "to serve patients well," believed ADs "help staff know or implement a patient's wishes," and wanted "to die when treatment is futile." Few Euro Americans believed "the system controls treatment," but most trusted the system "to serve patients well," had particular wishes about life support, other care, and acceptable outcomes, and believed ADs "help staff know or implement a patient's wishes." Most African Americans believed "the health system controls treatment," few trusted the system "to serve patients well," and most believed they should "wait until very sick to express treatment wishes."

CONCLUSION: While grounded in values that may compose part of American core culture, advance care planning may need tailoring to a patient's specific ethnic views.

KEY WORDS: culture; cross-cultural comparison; advance directives; terminal care; attitude toward death.

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Modern medicine saves lives but often at high financial, physical, and emotional costs.¹ The specter of these costs prompts many patients to consider refusing life support ahead of time. The official process of deciding about future treatment before it is needed is known as advance care planning.

To date, most systematic attempts at advance care planning have involved advance directives (ADs), documents in which patients express their treatment wishes for times of future incompetence. When introduced in the 1970s and '80s, ADs met with great enthusiasm. The popular press and medical literature quickly endorsed them. Almost all states codified ADs, and the federal government passed a 1990 law promoting them. Several versions of ADs were developed and widely disseminated.

But despite their promise and promotion, ADs have had limited impact on end-of-life care.²⁻⁵ One reason is that few Americans sign them; except in a few subgroups,⁶⁻¹⁰ just 4% to 25% of people surveyed have completed ADs.¹¹⁻¹⁸ While many AD advocates blame the low completion rates on inadequate patient or staff education and on low availability of AD forms,^{7,16,17,19,20} sensible interventions addressing those possible explanations boost AD completion rates very little.^{10,20-22} In addition, even if patients do execute ADs or express their end-of-life care wishes in other ways, health professionals may not know^{8,23,24} or honor those wishes in a crisis.³

We suspect culture has an important impact on a patient's decision whether to perform advance care planning.²⁵⁻²⁸ We define culture as the values, beliefs, and behaviors that a people hold in common, transmit across generations, and use to interpret their experiences.²⁹ Prior studies have identified broad cultural predispositions that may encourage or discourage AD use. For example, among Euro Americans and African Americans, a preference for making decisions as individuals and a familiarity with ADs may encourage AD use. But among Mexican Americans and other Hispanics, a preference for making decisions as families and a relative unfamiliarity with ADs may discourage AD use.^{30,31}

While important, such insights are too sketchy to provide health professionals much guidance in end-of-life care. For that reason, we undertook the present study to begin to characterize relevant cultural attitudes in enough detail to enable health professionals to conduct culturally specific advance care planning. ADs served as a concrete

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focus for the study. We aimed to produce recommendations, though preliminary and requiring future confirmation, for actual patient care. Our results suggest that because American ethnic cultures share some beliefs about terminal care but differ on many others, advance care planning should be tailored to each patient's specific cultural attitudes.

METHODS

In 1994–95 we surveyed Mexican-American, Euro-American, and African-American inpatients on the general medicine wards at 2 San Antonio, Texas, hospitals—one a university-affiliated, county hospital and the other an unaffiliated, private hospital. The city's population at the time included 55% Mexican Americans, 36% Euro Americans, and 7% African Americans.³² We defined subjects' ethnic group membership by a validated algorithm.³³ This algorithm uses ethnic self-identification, parents' surnames and birthplaces, and grandparents' ethnic backgrounds to classify subjects with high sensitivity, specificity, and reliability.

We limited subjects by age and diagnosis. Subjects had to fall between ages 50 and 79 because we believed end-of-life issues have the greatest impact on that age group. And subjects had to have at least 1 of the hospitals' 10 most common diagnoses requiring an average stay over 2 days—long enough to conduct the interviews during hospitalization. Among patients who met these 2 criteria, we used purposeful, nonstatistical sampling to ensure a wide range of views.³⁴ In particular, we sampled purposefully by gender and age greater or less than 65 to explore any differences between men and women and between older and younger subjects.

We hired 2 interviewers for their cultural sensitivity and fluency in English and Spanish. We trained the interviewers by critiquing their interviews first of us and then of volunteers not in the final sample. Several times each week an interviewer scanned the hospital admissions for eligible patients. After receiving permission from the admitting physician, the interviewer asked the patient for an interview. Institutional review boards at the 2 hospitals and the University of Texas approved our informed consent procedures.

The hour-long interviews elicited the subject's attitudes about ADs in a standardized way. First, the interviewer asked whether the subject had ever heard of ADs before. Next, the interviewer read in succession simple definitions of ADs in general and of 2 specific types of ADs—directives to physicians and durable powers of attorney for health matters. We defined an AD as any document that "tells the doctor what care the patient wants in the future"; a directive to physicians as an AD that helps the patient "tell the doctor whether the patient, when dying, wants to be kept alive or to be allowed to die"; and a durable power of attorney as an AD that "allows the patient to pick someone to decide things in case the patient ever becomes

too sick to decide for him- or herself." After each definition, the interviewer asked the subject what that AD meant to the subject, how the subject felt about it, and whether the subject would sign one.

We developed the interview schedule in English, translated it into Spanish, checked the Spanish translation with 2 independent reviewers, and pretested both versions. According to subject preference, 46 interviews used English only; 2, Spanish only; and 10, both languages. Bilingual typists transcribed the interviews from audiotapes and translated the Spanish parts into English. The transcription supervisor and 1 author (JDC) checked translations for accuracy.

Four coders of different genders, ethnicities, and professional disciplines content-analyzed the transcripts in 4 steps designed to let subjects' responses speak for themselves. In each step, 2 blinded coders independently coded responses in the same random order and then met to resolve disagreements. First, 2 coders (HSP and CMAG) eliminated any comments irrelevant to end-of-life care. Second, the same 2 coders identified from the remaining comments any about ADs. Third, these same coders reread all comments about ADs and devised a list of themes for coding. (We considered these themes to reflect subjects' views about ADs.) Our list was conservative: proposed themes made the list only if both coders agreed. By the time they finished rereading all AD comments, the coders could identify no new themes. Hence, the list had reached "saturation." And fourth, 1 original coder (HSP) and a new coder (AG) used the list to analyze each transcript. A fourth coder (HPH) resolved any disagreements. We considered a theme "present" for a subject if it appeared anywhere in his or her interview. Definitive determination of theme presence required agreement between 2 of the last 3 coders.

At the outset, we decided to report as "significant" only those themes mentioned by 50% or more of at least 1 ethnic group. Two reasons supported our 50% cut-off. First, we believed that at least 50% must accept a belief to consider it a characteristic of the group's culture, not just idiosyncratic to a few subjects. And second, we believed that at the 50% threshold many health professionals would change their terminal care practices to accommodate a belief. Nonetheless, we realize the 50% cut-off is somewhat arbitrary.

A nurse, blinded to the content analysis, reviewed each subject's medical record for documentation, required under federal law, that staff had discussed ADs with the subject on admission.

RESULTS

We identified 65 eligible subjects. Five subjects did not complete the interview, and 2 other subjects could not be classified distinctly into 1 of the 3 ethnic groups. Excluding these 7 subjects, 58 remained for analysis.

The ethnic algorithm identified those 58 subjects as 26 Mexican Americans, 18 Euro Americans, and 14 African

Americans. The 3 groups were similar in age, gender, and employment status (Table 1). Congestive heart failure and angina were the most common diagnoses. The groups differed by religion, marital status, education, occupational group, and socioeconomic status. The Mexican Americans tended to be Roman Catholic, married, educated through grade school, and having worked at blue-collar jobs. The Euro Americans tended to be Protestant, unmarried, educated through high school, and having worked at white-collar jobs. And the African Americans tended to be Protestant, unmarried, educated partially through high school, and having worked at service jobs. The Mexican

Americans and African Americans scored very low and the Euro Americans moderately low on the Duncan Socioeconomic Index.

Only 1 Mexican American and 2 Euro Americans had signed ADs before admission. Among the other 55 subjects, 69% of Euro Americans but only 12% of Mexican Americans and 29% of African Americans had heard about ADs. Furthermore, while medical records documented staff discussions about ADs with most patients from each group on admission (84% for Mexican Americans, 81% for Euro Americans, and 79% for African Americans), few subjects recalled those discussions (21% of Mexican Americans, 31% of Euro Americans, and 21% of African Americans).

Our content analysis identified 82 themes about advance care planning, but we report just the 25 “significant” by the 50% cut-off rule. We classify these themes under 4 major topics—treatment wishes, expression of treatment wishes, advance directives, and decision-making about terminal care. Tables 2–4 provide a sample of quotes for each theme. The themes use “subject” to mean the specific person interviewed, and “patient” to mean patients in general.

The 3 ethnic groups shared 6 themes, possibly reflecting a common American core culture (Table 2). Most subjects in all 3 groups had views about life and death that influenced their treatment wishes, and most preferred a particular family member as proxy. Most subjects in all 3 groups also liked some aspects of ADs, thought ADs improve the chances that a patient’s treatment wishes will be followed, and believed that the patient (or the proxy) deserves a say in treatment. In addition, most subjects in all 3 groups answered some questions about ADs with a theme—perhaps an artifact of our analysis—expressing the belief that their treatment wishes would be followed but failed to mention explicitly in those answers a link between their belief and ADs.

The 3 groups also shared misconceptions about ADs and anticipated obstacles to using them. The most widespread misconceptions were that ADs are testamentary wills or treatment consents, require an attorney, and concern funeral or burial arrangements. The anticipated obstacles to using ADs included lack of staff explanation of ADs, subject inattentiveness to explanations, anticipated bureaucratic obstacles, and fear that ADs could harm the patient.

The groups differed on the other 19 themes, probably reflecting specific ethnic cultures. Some of these themes distinguished 2 groups that shared the theme from the third group that did not (Table 3). For example, Mexican Americans and Euro Americans shared 6 themes—the wish for no life support; the beliefs that ADs can help staff know or implement a patient’s wishes, that ADs can prevent unwanted life support, and that the health care system will honor ADs because they are written; the influence of past illnesses on the subject’s present beliefs about ADs; and the belief that the health care system serves patients well during terminal care. Mexican Americans and African

Table 1. Subject Characteristics

Characteristic	Mexican Americans (n = 26)	Euro Americans (n = 18)	African Americans (n = 14)
Mean age, y	63	63	59
Women, %*	46	61	50
Diagnoses, %*			
Congestive heart failure	31	33	36
Angina	31	28	29
Other	38	39	36
Religion, %*			
Roman Catholic	77	39	0
Protestant	15	50	93
Other	8	11	7
Marital status, %*			
Married	54	28	21
Widowed	15	28	29
Divorced or separated	23	39	29
Never married	8	6	21
Median education	Completed grade school	Completed high school	Some high school
Occupational group, %*			
White collar	15	50	7
Service	23	17	57
Blue collar	42	22	36
Homemaker	19	11	0
Employment status (excluding homemakers), %*			
Currently employed	33	25	29
Retired	33	44	7
Disabled	24	31	57
Unemployed or other	10	0	7
Duncan SEI, median†	21	29	21

* Percentages are calculated within ethnic groups. For characteristics with multiple levels (such as diagnoses), totals may not sum to 100% due to rounding.

† The Duncan Socioeconomic Index (SEI), a scale based on occupational prestige and ranging from 1 to 99, is the most widely used method for expressing socioeconomic status in the United States. SEI scores for our subjects ranged from 15—the score for private household servants, solderers, and shoe machine operators—to 82—the score for pharmacists, postsecondary teachers, and petroleum engineers—and had a median of 23—the score for light truck drivers, animal caretakers, and parking lot attendants.

Table 2. Examples of Themes Shared by All Three Groups

Treatment wishes

Subject's views about life and death influence treatment wishes. Example from a Euro American:

Subject: "(Prolonging life) is not love. That is pity. And I wouldn't want to live on pity.... If I had to die, it would make me happy knowing (my daughter) was ending my life to make her life better.... I'm not afraid to die... You have to know when to let go."

Subject prefers a particular family member as proxy. Example from a Mexican American:

Interviewer*: "If you were too sick to tell the doctors and nurses what you wanted, who would you want to talk to them on your behalf?"

Subject: "If my husband was still alive, him."

Advance directives

Subject likes some aspects of ADs. Example from an African American:

Subject: "I hope (an AD) means what I think it means. That stops my kin, my kids, from blocking life and death, putting that life saver on me.... That's what it is? Oh, good.... I feel real good about that."

ADs improve the chances that a patient's treatment wishes will be followed. Example from an African American:

Interviewer: "Do you think the doctors are more likely to do ... what you want if you sign the directive to physicians than if you don't?... "

Subject: "... they should. They honor a man's agreement and his will."

Decision making about terminal care

Patient (or proxy) deserves a say in treatment. Example from a Euro American:

Interviewer: "Do you think the doctors are more likely to do what you want if you sign the directive to physicians?... "

Subject: "Of course, your doctor is going to do what you want.... Because that's their duty.... Why, of course, he does what his patient wants."

Subject believes his/her treatment wishes will be followed, but subject fails to mention explicitly a link between this belief and ADs. Example from a Mexican American:

Interviewer: "... do you think that the hospital will be more likely to do what you want ... if you sign one of these ADs?"

Subject: "Yes ... because it's part of their work, their job."

Misconceptions about advance directives

ADs are testamentary wills. Example from a Mexican American:

Interviewer: "An AD or Living Will is a piece of paper that helps you tell the doctor what care you want in the future."

Subject: "... I think that I should have a will because of my kids."

Interviewer: "What kind of will are you talking about?"

Subject: "When I die, like what to do with my things... That's not it?"

Interviewer: "No, that's a property will. ... This is just for health care."

ADs are treatment consents. Example from an African American:

Interviewer: "Do you think the hospital is more likely to do what you want if you sign the AD to physicians than if you don't?... "

Subject: "I've signed papers of many types. If something happened to me by myself here, I might bleed to death.... I signed it. I gave my consent. I pulled through so far."

ADs require an attorney. Example from a Mexican American:

Subject: "... you're giving some attorney power to tell the doctor what to do with you."

ADs concern funeral or burial arrangements. Example from a Euroamerican:

Interviewer: "What have you heard about the AD or Living Will?"

Subject: "All of my stuff is at the undertaker parlor right now. My decisions have been made.... "

Obstacles to using advance directives

Lack of staff explanation of ADs; example from a Euro American:

Interviewer: "When you came into the hospital, did anyone from the hospital staff talk to you about ADs or Living Wills?"

Subject: "Not this time, not yet. Oh, I'm sorry. They brought a paper and laid it on.... "

Interviewer: "... They didn't say anything to you? They just brought the paper?"

Subject: "Yeah."

Subject inattentiveness to explanations; example from a Mexican American:

Interviewer: "When you came into the hospital, did the nurse talk to you about ADs?... "

Subject: "... she told me I had to have a doctor or a nurse understand something. And be sure that he gets it or signs it... or I don't know. I didn't pay too much attention.... "

Difficulties with reading AD brochure; example from a Euro American:

Subject: "... when (the nurses) first come to visit you, they bring all of this literature... a Living Will, and I just never had anybody come... and talk to me about it.... And I didn't get much out of it. I'm not very good at reading."

Anticipated bureaucratic obstacles; example from a Mexican American:

Subject: "The hospital would probably (do) what you want if they get the right (AD) papers with the right person. It just seems like too many people handling too many things. And they get it mixed up and turned around.... "

Difficulties in finding a proxy who will carry out the patient's wishes;[†] example from an African American:

Subject: "When I do have another statement fixed out like that, I'm gonna let my daughter know, but not that son of mine, cause... he gonna fight it.... But if she knows that I was gone... and didn't tell him, that boy will make that child's life miserable."

(Continued)

Table 2. (Continued)

Uncertainty for patient in predicting his/her future treatment wishes accurately; example from a Euro American: Subject: "How are you going to get somebody to tell you what cares you want? ... you don't know. You're okay right now. ... You don't know what you're going to tell them until (the crisis) happens, right?"
Prior difficulties with using ADs; example from an African American: Interviewer: "When you came to the hospital, did anyone from the hospital staff talk to you about ADs or Living Wills?" Subject: "No, they gave me a paper. I glanced through it, but they kept sticking me so much, I didn't get a chance to finish nothing. I got it in my bag. Take it home."
Fear that ADs could harm patient; example from an African American: Interviewer: "Can you give me in your own words what you think this directive to physicians means?" Subject: "I just got through telling you, 'I want to live. I don't want to die.' I want to live as long as God lets me. I don't want no doctors to give me medicine to die."

* We include the interviewer's questions whenever they are necessary to understand the subject's comments.

† This theme includes comments about the difficulties of finding a trustworthy proxy who will press the patient's wishes, and qualms about burdening the proxy with decisions.

AD, advance directive.

Americans shared 4 themes—the influence of family dynamics on the choice of a proxy or the decisions a proxy may make, the lack of expression of treatment wishes to their physicians, the belief that the health care system controls treatment, and trust in their chosen proxies. Euro Americans and African Americans shared 2 themes—expression of treatment wishes to family and the belief that the existence of ADs just means the patient is imminently dying.

Still other themes distinguished each group uniquely (Table 4). Mexican Americans wished to be allowed to die when treatment is futile and admitted they had not told such wishes to anyone. Euro Americans expressed wishes about care other than life support (often about where or when they wished to die), described unacceptable treatment outcomes, said they had expressed wishes about care or outcome to specific others, and cited the usefulness of ADs in certain situations. And African Americans believed they should wait until very sick to express their treatment wishes.

DISCUSSION

Because death is a difficult, universal human experience,⁴ the essence of any culture necessarily includes beliefs about dying. Thus, we expected such beliefs to help define elements of an American core culture and its ethnic subcultures. Our study supports this expectation. The 6 themes shared across our ethnic groups (Tables 2 and 5) distill into 2 beliefs, which may compose part of American core culture: dying patients (or their proxies) deserve a say in treatment, and advance planning can help guide that treatment. These core beliefs provide strong impetus for conducting advance care planning among all American ethnic groups.

Our study also revealed differences among ethnic groups. Mexican Americans believed that the health care system controls treatment but serves patients well, wanted no futile life support, had not heard about ADs before but believed they can help staff know or imple-

ment a patient's wishes, and realized the influence of family in terminal care situations but had not told anyone their wishes. Euro Americans believed the health care system serves patients well; expressed wishes about life support, other care, and outcomes; had heard about ADs before and considered them useful in promoting such wishes in specific situations; and had expressed their wishes to family. And African Americans believed the health care system controls treatment, had not heard of ADs before, realized the influence of family in terminal care situations, and said both that they had expressed their wishes to their families and that they wanted to wait until very sick to express their wishes, perhaps meaning to physicians. Such ethnic-specific beliefs may reflect each group's elaboration of the 2 core cultural beliefs.

This study supports major findings from prominent prior studies of cultural beliefs about dying.^{30,31,35,36} Some of these findings reflect beliefs shared across ethnic groups. For example, many Hispanics, Euro Americans, and African Americans like the intent of ADs to give patients control over their terminal care,^{30,36} think their wishes about life support should be honored, and prefer family members as proxies.^{30,31} Other supported findings reflect interethnic differences. For example, fewer Hispanics and African Americans than Euro Americans know about ADs,^{30,35} and fewer African Americans than Euro Americans support using ADs³⁷ and discuss their treatment wishes with their physicians.³⁶

But this study also points up the complexity of advance care planning. For example, this study identifies misconceptions about advance care planning (beyond the confusion about ADs as testamentary wills) and suggests obstacles to performing it. This study also suggests possible similarities and differences across ethnic groups in attitudes about such planning. For example, as we noted earlier, members of each group may have specific wishes about terminal care but express them at different times to different people—or not at all. Such insights can help in conducting advance care planning sensitively.

Table 3. Examples of Themes Shared by Only Two Groups**Themes shared by Mexican Americans and Euro Americans****Treatment wishes**

Subject wants no life support. Example from a Mexican American:

Subject: "If I'm going to die, I don't want to be kept with machines or nothing. . . . Let me go."

Advance directives

ADs help staff know or implement a patient's wishes. Example from a Euro American:

Interviewer*: "How do you feel about a directive to physicians?"

Subject: "It's something that they have to know how you feel. Otherwise, they'll try to keep you alive with machines, and there ain't no telling how long they could do that. . . . I think I would use it. . . . it would just be sort of a guideline for them to follow."

ADs can prevent life support. Example from a Euro American:

Subject: "If they don't have a (Living) Will, (the doctors) might do everything possible and humanly and medically technologically try."

Health care system honors ADs because they are written. Example from a Euro American:

Interviewer: "Do you think that the hospital is more likely to do what you want if you sign the directive to physicians than if you don't?"

Subject: "I would think so. . . . it's written in black and white."

Past illnesses influence subject's present beliefs about ADs. Example from a Mexican American:

Subject: "When I was sick the very first time, they asked my husband to talk to me. . . . in case if they couldn't do much for me, to start signing the papers. . . . they had told him. . . . that if they couldn't do much for me, it was better for me to sign the paper. . . . like you're unconscious and they put you on that machine with tubes. . . . He came and talked to me. What did I think? If I wanted to go ahead and sign it. And I never did sign anything. I asked him, 'Am I gonna die?' (The directive to physicians) helps me to decide . . . in case I'm real sick . . . whatever they want me to sign. Whatever they make me sign sometimes."

Decision making about terminal care

Health care system serves patients well. Example from a Mexican American:

Subject: "I figure the doctors that I have right now, they know what they're doing. They want to get me well."

Themes shared by Mexican Americans and African Americans**Treatment wishes**

Family dynamics influences choice of proxy or decisions proxy may make. Example from a Mexican American:

Interviewer: "How do you feel about . . . giving someone the right? . . ."

Subject: "Primarily my sons, the men because we, the men, . . . move more rapidly. . . . I don't discriminate with my daughters. . . . they're adventurous. Anyway, the right you give it to the man. . . . To the man because the woman could have other commitments in the home, especially when there's a family. . . . (the men) divide their time working. I did it when I had to make my mother's arrangements for Social Security. . . ."

Expression of treatment wishes

Subject has not told wishes to physician. Example from an African American:

Interviewer: "Have you told (your doctors) . . . what treatments you want?"

Subject: "No. . . . I don't trust them with my business. I go out there with what's hurting me or what's bothering me, and that's enough for them to know what to treat me for."

Decision making about terminal care

Health care system controls treatment. Example from a Mexican American:

Subject: "The doctors should know what treatments I'm going to get. We don't tell the doctors what to do."

Subject trusts chosen proxy. Example from an African American:

Interviewer: "If you were too sick to tell the doctors or nurses what you wanted, who would you want to talk to them for you? . . ."

Subject: "I would want them to talk to Mrs. Meadows. . . . She's no kin to me. . . . just a friend of mine. . . . I think she would (do what I want). . . . I just have confidence in her."

Themes shared by Euro Americans and African Americans**Expression of treatment wishes**

Subject has told wishes to family. Example from a Euro American:

Interviewer: "Have you talked (with your husband) . . . about what you want the hospital or the doctors to do in case you become too sick you couldn't talk to them yourself?"

Subject: "Yes, we have. In fact, we were in a very serious accident in 1977, and (my husband had) been wanting them to just let him die. . . . So we've learned since that time . . . like I've told him, if something does happen, this and this and this, or whatever.

So we're able to talk about it."

Advance directives

Existence of ADs just means patient is imminently dying. Example from an African American:

Interviewer: ". . . what could you tell me is a directive to physicians?"

Subject: "It's to give the doctors an okay if in case I'm at a point where I'm dead really and they put me on a machine. To take it off."

* We include the interviewer's questions whenever they are necessary to understand the subject's comments.

AD, advance directive.

Table 4. Examples of Themes Unique to Each Ethnic Group

Unique to Mexican Americans

Treatment wishes

Subject wants to be allowed to die when treatment is futile. Example:

Subject: "I don't want no respirator. . . . If I can be revived, fine. If not, . . . let me go, . . . (The doctors) try their best. And if they can't get me to revive. . . , then instead of letting me suffer, they (should stop)."

Expression of treatment wishes

Subject has not told wishes to anyone (including family, physician, and others). Example:

Interviewer*: "Have you talked to anyone (family, friend, priest, or doctor) . . . about which treatments you would want?"

Subject: "No. . . . This is the first time we go through this."

Unique to Euro Americans

Treatment wishes

Subject expresses wishes about care other than life support. Example:

Subject: "I don't want to be a . . . weight on anybody. My son can't keep me. (My niece) can't keep me. I don't want to go on to a rest home. . . . I told my son . . . I would cut my wrists and bleed to death."

Subject describes unacceptable treatment outcomes. Example:

Subject: "If you're critical (and) you can't do nothing for yourself no more, you might as well pass away."

Expression of treatment wishes

Subject has expressed wishes about care or outcome to specific others. Examples:

Subject: "I've talked to my daughter . . . about the doctors' prolonging it. I told her, 'I've suffered too many years in my life . . . if several doctors say that they can't do anything, then don't keep me suffering' . . ."

Advance directives

ADs are useful when . . .

Patient is critically ill. Example:

Subject: "(An AD tells) the docs what you expect them to do for you . . . when you're maybe going to die. They suspect you're going to die. . . . I leave (the decision to stop life support) in their hands unless it's running too long. Then I have written so my folks can step in. . . . There are some doctors that do not believe in helping you go. . . ."

Patient wants no mechanical life support. Example:

Subject: "If I'm living on machines, then I want to stop. But (living on machines) won't happen because of the Living Will."

Patient cannot make decisions or function in other important ways. Example:

Subject: "(A durable power of attorney for health matters) gives them the right to make decisions when I can't. One of my kids or whoever I appoint. . . . like when my dad died . . . he didn't want any life support at all. . . . and I wouldn't either. . . ."

Unique to African Americans

Expression of treatment wishes

Subject should wait until very sick to express treatment wishes. Example:

Interviewer: "Have you talked to anyone about which treatments you want in case you become too sick to tell the hospitals or the doctors yourself?"

Subject: "You don't talk that kind of way. That's bad for you. . . . You don't know where you're going. You might not even be in sickness then. . . . Wait 'til the day comes."

* We include the interviewer's questions whenever they are necessary to understand the subject's comments.

AD, advance directive.

Our study has both limitations and strengths. One limitation is the lack of generalizability from a nonstatistical, purposive sampling. We chose this sampling to elicit a broad range of views, from which we can generate hypotheses for future statistical testing. Another limitation is the potential confounding between ethnic group and education, religion, marital status, and occupational group. Small numbers prevented us from ruling out such confounding. Yet prior studies have shown ethnicity to be better than education, religion, and socioeconomic status (a measure of education and income) in predicting patients' life support wishes^{30,36} and better than education and religion in predicting intent to complete ADs.³⁶ No studies have specifically pursued confounding by marital status or occupational group. Future studies must assess such potential confounders. A third limitation is the possible inconsistencies in what a subject says or between what a subject says and thinks. People may think illogically or

may not accurately disclose their views, especially if unpopular. No interview study escapes these problems completely. And a fourth possible limitation is the lack of strict ethnic matching between subject and interviewer. Yet such matching, while seeming beneficial in theory, has failed to show benefit in practice.³⁶

Our study also has important strengths. One is the open-ended interview, which allowed subjects to respond in their own words. We reasoned such responses would portray subjects' views most accurately. Another strength is subjects' somewhat old, ill state—making death for them real, not abstract or remote. Subjects had probably thought about their deaths even before our interviews. Still another is the validated algorithm that identifies ethnic group membership accurately and reliably with little reliance on subjective judgments.^{33,38} Yet another strength is the use of bilingual interviews that allowed subjects to respond in English, Spanish, or both. Fluency

Table 5. Summary of Themes by Ethnic Group

Topic and Theme	Mexican American	Euro American	African American
Treatment wishes			
Views about life and death influence wishes.	X	X	X
Subject prefers particular family member as proxy.	X	X	X
Family dynamics influences choice of proxy or decisions proxy may make.	X		X
Subject wants no life support.	X	X	
Subject wants to be allowed to die when treatment is futile.	X		
Subject expresses wishes about care other than life support.		X	
Subject describes unacceptable outcomes.		X	
Expression of treatment wishes			
Subject has told wishes to family.		X	X
Subject has told wishes to specific others.		X	
Subject has not told wishes to physician.	X		X
Subject has not told wishes to anyone.	X		
Subject should wait until very sick to express wishes.			X
Advance directives			
Subject likes some aspects of ADs.	X	X	X
ADs improve chances that patient's wishes will be followed.	X	X	X
ADs are useful when ...			
Patient is critically ill.		X	
Patient wants no mechanical life support.		X	
Patient cannot make decisions or function in other important ways.		X	
ADs help staff know or implement patient's wishes.	X	X	
Health care system honors ADs because they are written.	X	X	
ADs can prevent life support.	X	X	
Past illnesses influence present beliefs about ADs.	X	X	
Existence of ADs means patient is imminently dying.		X	X
Decision making about terminal care			
Health care system controls treatment.	X		X
Patient (or proxy) deserves a say in treatment.	X	X	X
Subject believes his/her wishes will be followed, but fails to link explicitly this belief to ADs.	X	X	X
Health care system serves patients well.	X	X	
Subject trusts chosen proxy.	X		X

AD, advance directive.

and language-specific connotations probably enabled some subjects to express abstract and emotion-laden concepts more easily and accurately in one language than the other. But perhaps the most important strength of the study is the extensive precautions we took to minimize idiosyncratic bias in analyzing the interviews. We chose diverse coders, had them read interviews independently, and required consensus to consider a theme present.

IMPLICATIONS FOR ADVANCE CARE PLANNING

This study lends an important perspective to Americans' attitudes about advance care planning: both similarities and differences exist across ethnic groups. The similarities probably reflect a common American core culture; the differences, specific ethnic cultures. Optimal advance care planning surely requires attention to both.

The two beliefs that may belong to American core culture—dying patients (or their proxies) deserve a say in treatment, and advance care planning can help guide that treatment—have prompted the development of ADs. While

a logical first step in fulfilling those beliefs, ADs have had limited use. They may just not suit many patients,⁵ and perhaps ethnic culture explains different receptivities to ADs. Euro Americans may be most receptive to the concept. Prior research indicates Euro Americans prefer individual, patient-centered decision making about terminal care.^{31,35} That research and ours suggest Euro Americans expect some control over their care, and trust the health care system to serve a patient's wishes. That expectation may spur Euro Americans to try to exert control over their terminal care through ADs.

In contrast, Mexican Americans and African Americans may be less receptive to ADs. One possible explanation applies to both groups: both may believe that the health care system controls treatment and that communicating one's wishes to care givers is therefore pointless. But other possible explanations differ between the groups. Prior research indicates Mexican Americans prefer family-centered decision making about terminal care.^{31,35} Our study supports this idea by suggesting that Mexican Americans perceive family influence over terminal care, and trust families and the health care system to

serve a patient's interests well. Still, even though Mexican Americans do not want futile life support, they have not told those wishes to anyone. Perhaps Mexican Americans assume their family members know their wishes without being told and, thus, ADs are unnecessary.

Unlike Mexican Americans, African Americans may disclose their wishes—readily to their families but only reluctantly to their physicians. Prior research indicates that African Americans, like Euro Americans, prefer individual patient-centered decision making.^{31,35} But our research suggests most African Americans believe the health care system controls treatment, and few trust the system to serve patients well. They do perceive family influence over terminal care and trust family to promote a patient's wishes. For that reason, African Americans may readily disclose their terminal care wishes to their families. Yet wariness toward the system may keep African Americans from embracing the AD concept and make them wait until very sick to disclose such wishes to physicians.

Thus, health professionals face the challenge of adapting advance care planning to patients' ethnic and idiosyncratic beliefs. We believe that while advance care planning is not limited to ADs, past experience with them can teach valuable lessons about improving the cultural sensitivity of the advance care planning process. Our results, though preliminary and needing verification, offer some clues, formulated here as 3 general recommendations and some other ethnic-specific recommendations.

The 2 beliefs shared by all 3 ethnic groups here and possibly reflecting parts of American core culture form the basis for our general recommendations. First, physicians should make advance care planning a priority in their patient care.³⁹ While all 3 ethnic groups in our study believed that patients deserve a say in their treatment and that advance care planning can affect treatment, prior studies indicate that physicians rarely initiate advance care planning,¹¹ know patients' wishes,^{8,23,24} or use them to guide treatment.^{2,3} Thus, physicians appear unmotivated to pursue and implement patients' wishes about terminal care. For advance care planning to succeed, physicians must commit to it wholeheartedly.

Second, physicians should take the initiative in conducting advance care planning. While respecting cultural diversity, physicians should try to persuade all patients to perform advance care planning and should take simple steps to facilitate the process.^{28,40} For example, physicians should provide educational materials about advance care planning and allot time to discuss it during patient visits. In the discussions, physicians should try to elicit patients' hopes, fears, and wishes about treatment and outcome.^{2,19,41–44} Above all, physicians should *listen* to patients.²¹ The aim of advance care planning should not be to convince patients to sign documents such as ADs but to help patients define and express their treatment wishes.^{45,46}

Third, physicians should work continuously to improve their approach to advance care planning.⁵ They

should try to identify and remove any obstacles to the process. Simple but important measures include anticipating and addressing possible misconceptions, ascertaining that educational materials read at the level and in the preferred language of patients, ensuring that the vision-impaired have their glasses available for reading, and including family members in discussions to the extent patients wish.⁴⁷

The differences among the 3 groups form the basis for our ethnic-specific recommendations. Because many Mexican Americans may have already decided against life support for future terminal illness but have not expressed those wishes, physicians should ask specifically about them. Physicians should also encourage Mexican Americans to express any such wishes to their families. Because many Euro Americans may have particular wishes about life support, other terminal care, and unacceptable outcomes, physicians should ask specifically about those wishes. Physicians should also describe ADs as a culturally accepted way to express such wishes. Finally, because African Americans may be wary of advance care planning, physicians should introduce it to them in a restrained, neutral way and respect any reluctance to discuss treatment wishes. Nonetheless, physicians should stay alert for African Americans' expression of their wishes near the end of life.

Formal research, perhaps using ADs as a tool, should continue to explore ethnic culture-based attitudes about dying.⁴⁸ We believe a general understanding of ethnic cultures offers an initial framework for exploring individual patients' attitudes. But that understanding is only a start, not an end, to the exploration. Physicians should realize that individual variation exists in any culture. And they should search diligently to learn each dying patient's needs, some of which may be rooted in ethnic culture. Then physicians should use that knowledge to adapt care to meet the patient's needs.

We believe the promise of advance care planning: terminal care can be tailored to individual patients' needs.^{22,49,50} Yet our study suggests that advance care planning, grounded in American core culture, will realize its full potential only when physicians consider the ethnic and idiosyncratic beliefs of each patient.

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